













Optimal clinical care pathway for adults: Epilepsy

National Neurosciences Advisory Group (NNAG)

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Overview: About the optimal pathway

This pathway is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group (NNAG).

The development of this pathway was overseen by NNAG, with input from professional bodies and patient organisations. A 6 week public consultation was held to gather input, views and experience from people affected by neurological conditions and wider stakeholders.

The pathways set out what good treatment, care and support looks like. This includes treatment and support for people who may be experiencing the first symptoms of a neurological condition, right through to people who have lived with a condition for a long time. They set out the aspirations for good care, support improvement of services and enable commissioning of quality services, locally and nationally.

Optimal Clinical Neuroscience Pathways



NEUROSCIENCE

SUBARACHNOID/INTRACRANIAL HAEMMORHAGE

MULTIPLE SCLEROSIS (MS)

EPILEPSY

AUTOIMMUNE

HEADACHE & FACIAL PAIN

NEUROMUSCULAR CONDITIONS

MOVEMENT DISORDERS

MOTOR NEURONE DISEASE (MND)

FUNCTIONAL NEUROLOGICAL DISORDER (FND)

TRAUMATIC BRAIN INJURY (TBI)



CROSS-CUTTING

TRANSITION FROM CHILDREN TO ADULT SERVICES

NEUROGENETICS

MENTAL HEALTH

REHABILITATION

FIND OUT MORE

Optimal clinical pathways and resources (NHS England and NHS Improvement. NHS log in required): www.future.nhs.uk/about

Optimal clinical pathways and resources (NNAG): www.nnag.org.uk/optimum-clinical-pathways

Neurological patient organisation websites & resources (Neurological Alliance): www.neural.org.uk/membership/our-members



VISIT WEBSITE



VISIT WEBSITE



VISIT WEBSITE

Executive summary

This optimal clinical pathway for adults with epilepsy (PWE) was designed by a working group of epilepsy specialist clinicians and charity representatives.

The group emphasises the need for PWE to be given access to a “first point of contact” with epilepsy expertise to triage care and provide local advice. The pathway is designed to keep as much care local when possible. As such, it specifies when patients need to be seen in a regional neuroscience centre and provides recommendations for step-down from tertiary and secondary services.

This pathway is expected to create efficiency savings while improving the quality of epilepsy services. Efficiency savings can be made with early diagnosis and attention to local management, both of which have been shown to reduce care costs while improving patient outcomes.

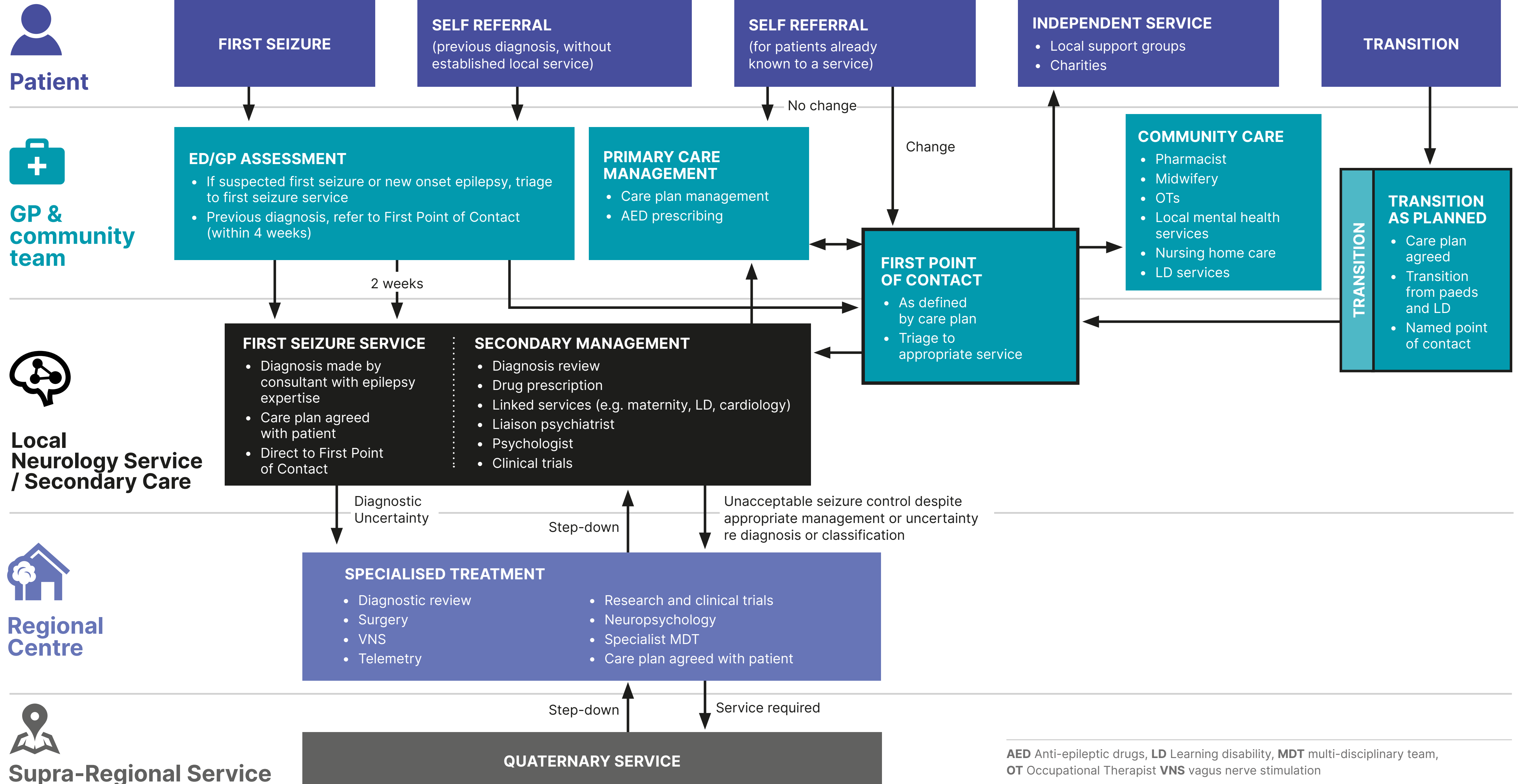
With current models of care, there are insufficient numbers of epilepsy specialist consultants and nurses to deliver a timely service in all areas. It is therefore important that the service addresses barriers in patient flow through the clinical pathway. Another barrier to the optimal pathway is the inability of centres to receive, store or share video monitoring and other patient information. Improving methods of information sharing between providers will facilitate early diagnosis and join up patient care.

Key enablers of the optimal pathway include specialist networking and virtual consultation. Additionally, increased focus on data sharing or a national epilepsy register or patient portal would greatly facilitate communication between clinicians and improve patient care.

The cognitive and mental health comorbidities of epilepsy are substantial and people with epilepsy should have access to integrated services, with access to neuropsychological mental health services across the pathway.



Pathway map 1: Referral pathways



INFORMATION, EDUCATION, ADVICE, SUPPORTED SELF-MANAGEMENT, SHARED DECISION MAKING, ACCESS TO RESEARCH OPPORTUNITIES AT ALL LEVELS

AED Anti-epileptic drugs, LD Learning disability, MDT multi-disciplinary team, OT Occupational Therapist VNS vagus nerve stimulation



Pathway map 2: Holistic care in epilepsy



GP & Community Team

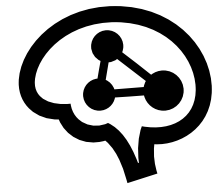
PERSON WITH EPILEPSY AND FAMILY

A&E/ACUTE CARE
• See [NCEPOD](#)

PRIMARY CARE & COMMUNITY PHARMACY

- Prescribing/monitoring
- Care Plan
- Red flags
- Chronic illness management

PERSON WITH SUSPECTED EPILEPSY AND FAMILY



Local Neurology & related Community & specialist Services

MATERNITY

LEARNING DISABILITY

NEUROPSYCHIATRY

ELDERLY CARE

OTHER SPECIALITIES

LOCAL EPILEPSY SERVICE

- Provides diagnosis, regular review, first point of contact, co-ordination of holistic care. MDT, admission review.
- On-site (community or hospital based) neurology-led specialist epilepsy clinics (first seizure assessment, follow-up, maternity and transition clinics)
- Specialist epilepsy nursing
- Care Planning
- Risk Assessment/SUDEP & seizure safety check
- Competencies/training incl care providers
- Help-Line (for patients and professionals)
- Local access to investigations: Imaging, EEG/Telemetry
- Social prescribing
- Social/psychological/patient organisation support

ALCOHOL AND DRUG ADDICTION SERVICES

SOCIAL SERVICES

PSYCHOLOGY

END OF LIFE CARE

BEREAVEMENT SERVICE

RESEARCH



Regional Centre

EPILEPSY SERVICE

- Second opinion
- Diagnostic
- Management review
- Monitoring
- Coordination of local epilepsy services
- Patient/clinical education (third sector can support)
- Access to VNS and surgery (inc. monitoring and follow-up)
- Access to non-standard medical therapies needing specialist support
- Access to clinical trials and research
- Neuropsychology

NCEPOD National Confidential Enquiry into Patient Outcome and Death, **MDT** multi-disciplinary team, **SUDEP** Sudden Unexpected Death in Epilepsy, **VNS** vagus nerve stimulation

INFORMATION, EDUCATION, ADVICE, SUPPORTED SELF-MANAGEMENT, SHARED DECISION MAKING, ACCESS TO RESEARCH OPPORTUNITIES AT ALL LEVELS

There is wide variation in access to specialised care across England and concerns over outcomes and groups facing health inequalities.

The percentage of unscheduled admissions treated in specialised centres ranges from 8.8-15.5%.

PWE are a third more likely to die prematurely in 2014 than they were in 2003, when compared to people without epilepsy (33% increase in the age standardised mortality rate) ^{1,2}.

PWE are more likely to have prolonged hospital stays (50% increase in inpatient admissions of over a fortnight from 2015/16 to 2017/18).

There has been an increasing admissions cost since 2015, likely due to longer lengths of stay and increases in emergency admissions rates ^{1,2}.

The incidence and prevalence of epilepsy is at least a third higher in the most deprived areas of the UK than the least deprived ³.

People living in more deprived areas are nearly three times as likely to die with epilepsy than those living in the least deprived areas ¹. The deprived are also more likely to die from their epilepsy ⁴.

PWE people with epilepsy

This document is the output of the Epilepsy Clinical Working Group's efforts to define the optimal pathway for patients with epilepsy. It outlines:

- The optimal pathway for patients with epilepsy from first seizure to ongoing management
- The definition of "specialised" epilepsy care
- A workforce model to support implementation
- Possible efficiency savings to come out of the optimal pathway
- Barriers and recommendations around patient flow, information sharing and research and clinical trials



Pathway: First seizure to diagnosis

Good practice

After a first suspected seizure, a patient should be referred to a first seizure service. This should involve being seen by a general neurologist, epilepsy medical specialist, or GP with epilepsy interest within 2 weeks, and receiving investigations (ECG, EEG, MRI) if indicated within another 2 weeks⁵. Local networking can facilitate correct referrals earlier (see page 9).

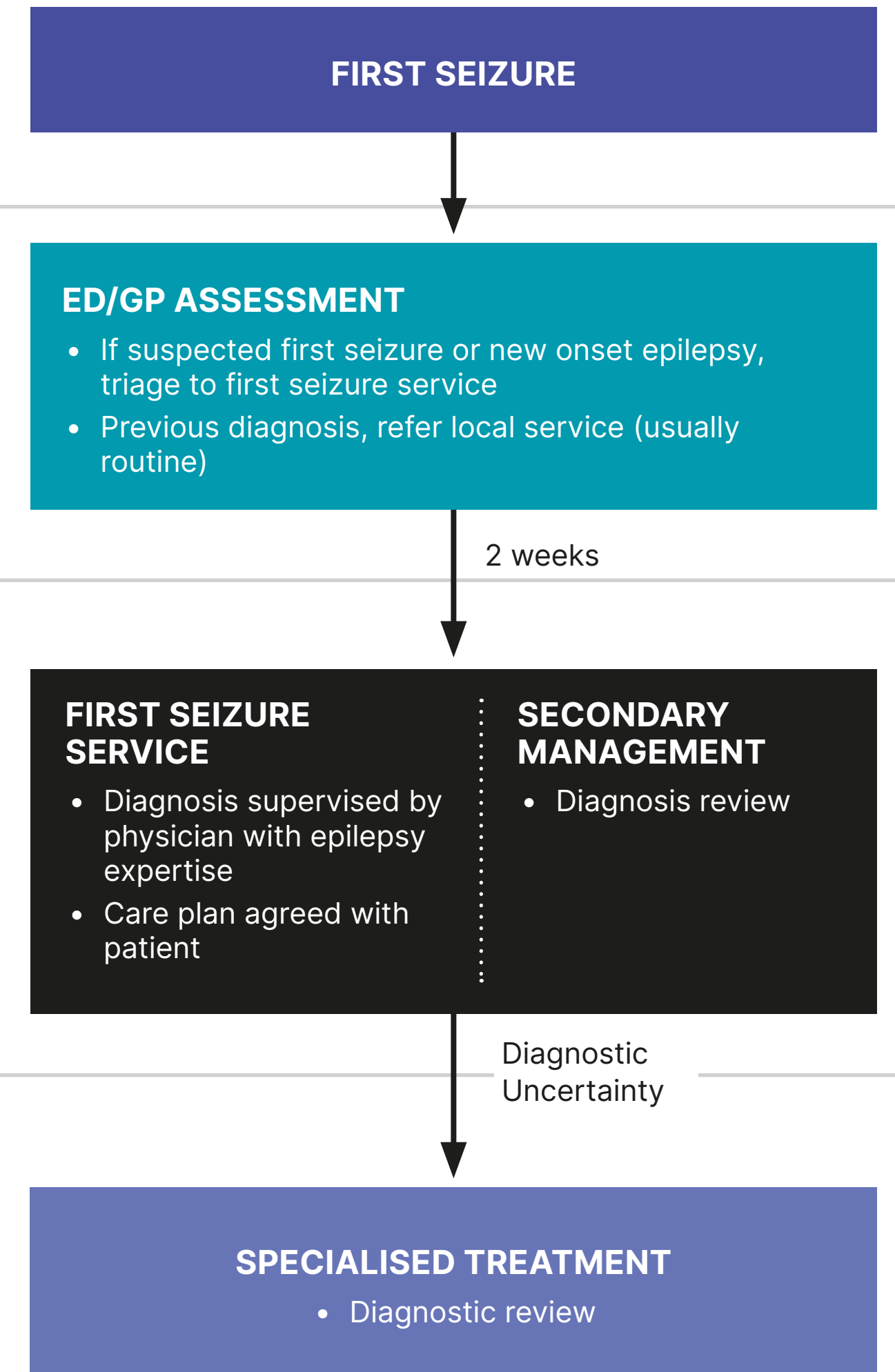
First seizure service

The patient should be seen in a first seizure clinic that is directly supervised by a physician with expertise in epilepsy. Virtual consultation is possible for some follow-up appointments and for addressing acute problems, especially if a patient needs to be kept local. Expertise in epilepsy may be demonstrated by the following:

- Training and continuing education in epilepsy
- Peer review of practice
- Epilepsy must be a significant part of their clinical workload (equivalent to at least one session

At diagnosis, the diagnosing physician should agree a care plan with the patient that includes the following:

- Diagnosis, including aetiology/syndrome, and identification of relevant comorbidities
- Anti-epileptic drug treatment and any planned or ongoing changes
- Seizure management plan with mortality risk communication and review
- First point of contact
- Place of safety to be taken in the community following seizure (other than medical facility)
- Rescue medication plan, where indicated
- Recommendations and signposting for independent support services
- Practical and/or psycho-social self-management actions agreed with patient and carers, with progress review plan that allows for additional support to be provided as needed





Pathway: Treatment and ongoing management

Good practice

- 1. A good epilepsy service will provide a patient with a “first point of contact” (FPOC)** A patient’s FPOC will be named in their care plan (see Appendix for more detail). The FPOC should have clinical expertise in epilepsy, typically an epilepsy specialist nurse or other suitably qualified healthcare professional. Once a patient is diagnosed with epilepsy and known to a local service, they will be able to contact their first point of contact to triage necessary care ⁶.
- 2. As much care as possible should be kept local.** A great deal of epilepsy care can be provided by GPs, including anti-epileptic drug prescription (on advice of a specialist), contraception and conception advice, mental healthcare, co-morbidities management, driving advice and DVLA forms ⁷. Referrals to secondary and tertiary care should only be made as needed.

A patient should be referred to tertiary care if they experience unacceptable seizure control despite appropriate management (i.e. has failed 2 anti-epileptic drugs), or if there is uncertainty regarding diagnosis or classification. A specialist may revisit

diagnosis, classify the epilepsy, consider surgery, consider alternative treatments and/or additional investigations to aid syndromic classification, analyse comorbidities and manage expectations.

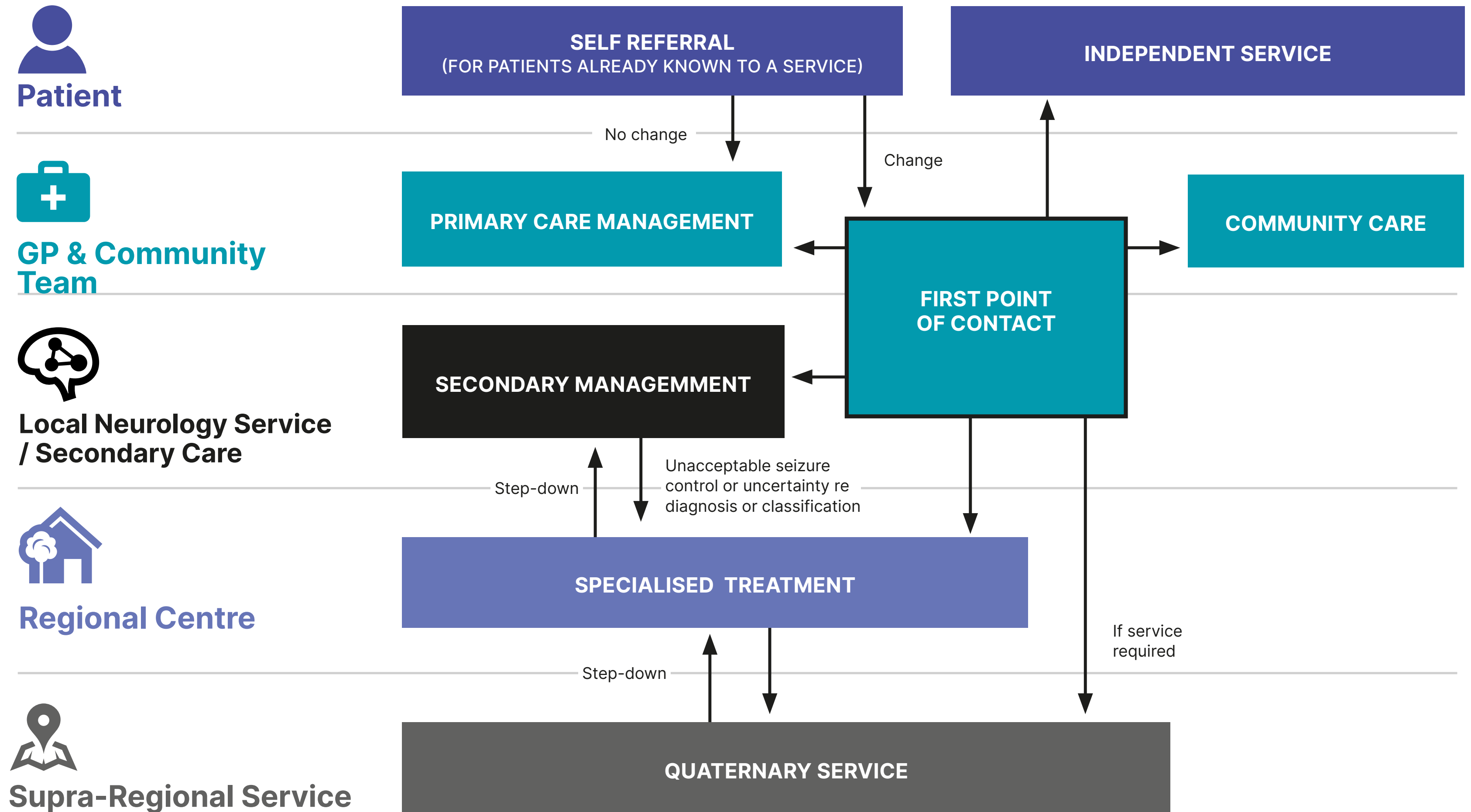
Step-down from tertiary service should occur as soon as possible. Currently, a patient may be kept unnecessarily in a tertiary service because tertiary specialists or patients lack confidence in secondary neurology service to provide adequate care. Similarly, secondary care or patients may lack confidence to share care with primary care. Strengthening networks by increasing local knowledge about alternatives to specialist care, and supporting efficient communication pathways between services (e.g. where there are general neurologists with epilepsy competency in a DGH) could help move patients closer to home.

- 3. Shared-decision making is integral to care of PWE.** Patients, families and carers should be provided with the necessary information and support to make decisions about their care, medication and treatment together with clinicians and based on the best available evidence. Shared decision making should be integral to high-quality, evidence-based and patient-centred care at every stage of the pathway.

Pathway: Treatment and ongoing management

Secondary care functions include the following:

- MDT approach
- Psychological support, links with 'liaison psychiatrists' embedded in secondary care hospitals who have specialist knowledge of the impact of physical health issues on mental health ⁸
- Diagnosis review
- Initiating AED prescription
- Linked services (e.g. maternity, LD, cardiology)
- Psychological support
- Clinical trials



Pathway: Defining specialised epilepsy service

While the majority of epilepsy care can be provided at primary and secondary levels, there are some services that must be provided in a specialised centre, and some patient groups are more likely to need specialised care.

Patient groups that may require specialised care or specific service models:

- Learning disability (this document uses the term “learning disability” in line with NHS England commissioning practice, but does not differentiate between learning and intellectual disability)
- Maternity
- Transition
- Elderly

Elements of specialised care: Tertiary

Tertiary services are provided by all specialised centres and are not available at district general hospitals.

- MDT approach
- 3T MRI and other advanced imaging reported by a neuroradiologist
- Neuropsychiatry and neuropsychology services
- Video EEG Telemetry service
- Research and clinical trials
- Surgery (typically temporal lobectomy, lesionectomy)
- Vagus nerve stimulation (VNS)
- Decision making and initialising non-standard medical therapies needing specialist support (e.g. ketogenic diet, cannabidiol CBD)
- Neurogenetics

Elements of specialised care: Quaternary

Quaternary services are considered ‘super specialised’ and are only provided at some specialised centres.

- MDT approach
- Invasive video EEG telemetry (stereo, depths, grids)
- Everolimus
- Single-photon emission computed tomography (SPECT)
- Positron emission tomography (PET) scan
- Complex surgical resections
- Capacity for long admissions for complex cases, e.g. Non-epileptic attack disorder (NEAD), LD and behaviour



Pathway: Efficiency savings



Early diagnosis

This pathway provides multiple recommendations to facilitate early diagnosis of epilepsy. Early diagnosis of epilepsy has been shown to lead to efficiency savings by getting patients on the correct treatment early. In a study by the European Project, economic modelling estimates savings from early diagnosis of £7,300 per person plus a 1.069 QALY increase over 70 years. The study attributes cost savings to speed at which patients are seen by a specialist and the effectiveness of specialist treatment ⁹.



Attention to patient management

This pathway highlights the importance of a local first point of contact for people with epilepsy, to provide clinical advice and triage appropriately. It is expected that this will help PWE manage their conditions locally and thus reduce cost through preventing unnecessary presentation at emergency services.

A similar model has been proposed in the Norfolk epilepsy community service. The business case describes how the service was able to increase WTE ESNs from 1.6 in 2016 to 4.5 in 2018, due to savings gained from decreased DNA rates, A&E attendances and outpatient appointments ¹⁰.

Barriers & enablers : Patient flow

With current models of care, there are insufficient numbers of epilepsy specialist consultants and nurses to deliver a timely service in all areas. It is therefore important that the service address barriers in patient flow through the clinical pathway.

Cross-cutting recommendation: Support for self management

Access to online self management programmes and support groups will help patients navigate the service.

Self-monitoring devices: If these were more widely used or promoted by clinicians they could help people with epilepsy improve self-management, and encourage appropriate engagement with services when a patient's epilepsy worsens, helping to avert crisis, e.g. A&E admissions or death.

- People and digital tools to help patients navigate the service
- People and digital tools to help self-manage condition in between appointments (e.g. charity apps with seizure diaries, or the risk self-monitoring app)
- People and digital tools to improve adherence, help with common comorbidities such as insomnia, mental health challenges such as anxiety

Barrier	Recommendation
The first barrier for patients with epilepsy is 'getting in the front door'. Only half of possible first seizure presentations to emergency departments are referred to a seizure and/or neurology clinic, and first seizures may not be prioritised over other presentations. ¹¹ A GP also may not see a patient who has been admitted to an emergency service for a seizure, and pathways to first seizure services may not be clear.	<ul style="list-style-type: none"> ■ Clear referral guidelines ■ GP education programmes ■ Audit - see NASH
Electronic referral systems are inadequate and fail to direct GPs to the correct clinics, and there is often inadequate triaging system in hospitals.	<ul style="list-style-type: none"> ■ The system should be overhauled to achieve a system that is managed under a two week rule, and facilitates referral to first point of contact for patients known to service.
Geography	<ul style="list-style-type: none"> ■ Teleconferencing and virtual consultation ■ Network of specialists linked virtually, operating in the community
Unclear definitions of who is responsible for patients when they leave service	<ul style="list-style-type: none"> ■ Clear referral guidelines

Barriers & enablers : Patient flow

Case study: St George's NHS Foundation Trust

Actors and workforce

Tertiary centre	<ul style="list-style-type: none"> ■ 3.6 WTE consultant neurologists with epilepsy special interest ■ 0.2 WTE Associate Specialist ■ 0.5 WTE Neuropsychologist ■ 3.0 WTE Epilepsy Nurse Specialists 	<ul style="list-style-type: none"> ■ Input from 2 consultant neurosurgeons ■ Neuropsychiatry service ■ Rotating specialist trainee ■ Secretarial support
Linked DGH services	<ul style="list-style-type: none"> ■ 6 DGHs in southwest London ■ 1 named consultant at each DGH with special interest in epilepsy ■ At least 1 epilepsy nurse specialist 	

Responsibilities

Tertiary management	<p>Surgery evaluations & MDT. Complex Case MDT:</p> <ul style="list-style-type: none"> ■ Epilepsy leads from tertiary centre and each DGH can bring patients. ■ Required for CBD, Everolimus, genetic testing. <p>Advice as needed when referred by epilepsy lead. Development of regional pathways, policies, information leaflets.</p>	<p>All group management meeting every 2-3 months</p> <p>Website with guidance documents</p>
DGH epilepsy lead	<p>Management of complex cases at DGH, with the option to bring patients to the Complex Case MDT. Gives advice to DGH general neurologists on epilepsy care. Development of local pathways, policies, leaflets.</p>	
Local management	<p>All ongoing medical care for PWE.</p>	

➔ Barriers & enablers : Information sharing

Improving methods of information sharing between providers will facilitate early diagnosis and join up patient care.

Barrier	Recommendation
Lack of standard protocol on imaging	<ul style="list-style-type: none"> ■ Minimum standards for epilepsy protocol MRI, with harmonisation between sites where possible
No system for sharing data amongst health system providers	<ul style="list-style-type: none"> ■ A standardised epilepsy database, preferably with video storage capability, would be incredibly useful for clinical research. ■ Integrated Electronic Health records between providers
Blockages to video sharing across Trusts slows diagnosis: <ul style="list-style-type: none"> ■ Trust rules ■ Patients unable to send videos into Trusts (files too big to email, cloud services blocked or insufficiently secure) ■ Too many discrete systems across Trusts (NHS-wide issue) ■ Platforms with video sharing have extra cost 	<ul style="list-style-type: none"> ■ Video sharing between patients and Trusts, and between Trusts ■ Cloud encrypted data transfer service

Video sharing

This document recommends enabling video sharing between patients and carers and their Trust, and between Trusts. Videos of events and seizures are vital diagnostic tools in epilepsy. As such, enabling video sharing is essential for patient care and can save time and money through avoiding diagnostic delay and unnecessary investigations. Enabling timely diagnosis will lead to better outcomes for patients and provide opportunity to invest funds elsewhere, e.g. specialist nurses and clinical research.

Barriers & enablers : Access to research and clinical trials

Investment in research and clinical trials is critical to improve epilepsy treatment. There is insufficient attention to neurology research and clinical trials in England and epilepsy research in particular.

In 2022 the National Brain Appeal survey found that 80% (n=634) of respondents had never been invited to take part in research relating to neurological conditions. 91% (n=698) of respondents said they would take part in research if offered the opportunity ¹². Public funding for health research has increased over the last 10 years but funding for neurology is down proportionately 2.5% ¹³. Furthermore, for every pound invested per person with Parkinson’s disease, 9p is spent per person with epilepsy ¹⁴.

The epilepsy clinical working group recommends the following to address barriers to research and clinical trials for epilepsy:

Barrier	Recommendation
Lack of capacity and incentives for Trusts to enable clinicians to participate in research. The main barrier is lack of time given heavy clinical workload in job plans.	<ul style="list-style-type: none"> ■ Identify and free up capacity ■ Joined up epilepsy registry/database that is linked to routine clinical care ■ Clinician and patient partnerships with epilepsy organisations to improve access to funding and PPI support for projects
Inadequate networks.	<ul style="list-style-type: none"> ■ Establish networks to build and deliver research programmes ■ Horizon scanning to identify research opportunities
Bias toward biomedical research.	<ul style="list-style-type: none"> ■ Forum for clinicians interested in health services and epilepsy ■ Ensure public involvement ■ Collection of standardised epilepsy data in NHS systems (with video storage) useful for service evaluation and research

Clinical guidance: To be considered alongside the pathway

Prescribing anti-epileptic drugs for people with epilepsy and learning disability

People with learning disabilities have higher prevalence of epilepsy than the general population, have higher levels of comorbid mental and physical disorders, and face greater barriers communicating their needs and wishes. This, coupled with greater likelihood of being resistant to treatment, leads to higher mortality rates for people with LD. Prescribing anti-epileptic drugs to people with LD can be difficult, due to LD patients being more susceptible to, and less able to communicate, side effects of drugs. Refer to the Step Together guidance, service evaluation toolkit and benchmarking tool (2020).

Useful Resources:

Step Together (2020) Integrating care for people with epilepsy and a learning disability

[VISIT WEBSITE](#)



Epilepsy Action. Step Together Benchmarking and Evaluation Toolkit

[VISIT WEBSITE](#)



Royal College of Psychiatrists (2017) Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability

[VISIT WEBSITE](#)



Watkins et al. (2019) Quality improvement in the management of people with epilepsy and intellectual disability: the development of clinical guidance. Expert Opinion on Pharmacotherapy

[VISIT WEBSITE](#)

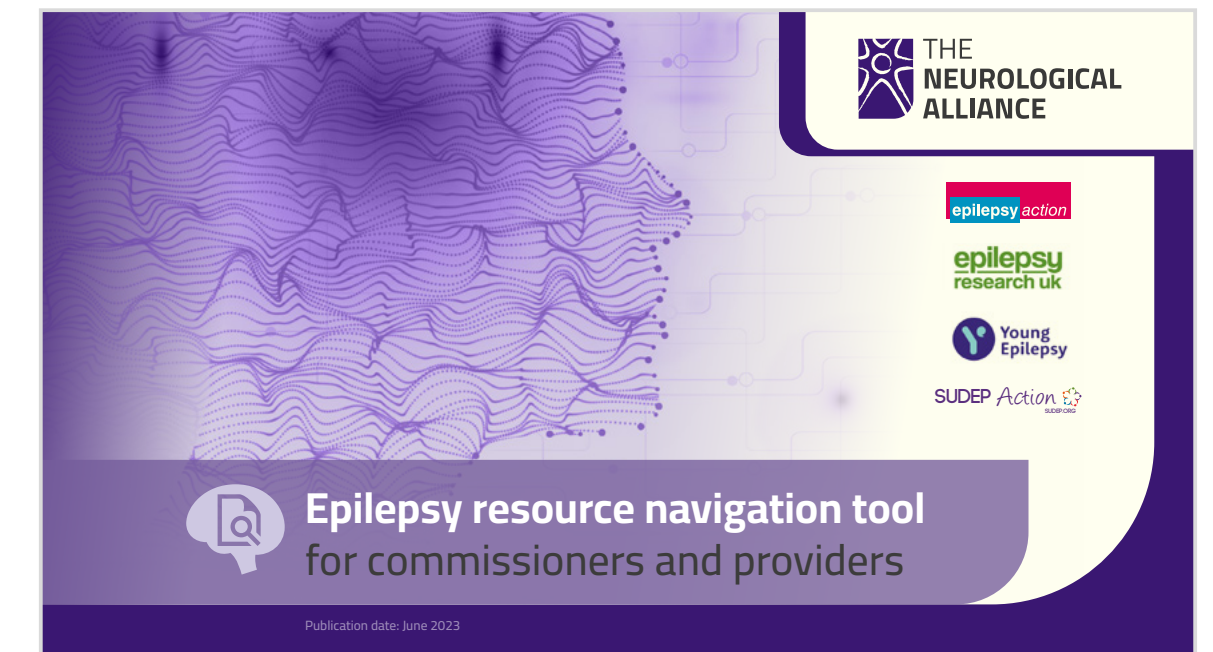


Commissioning tool: To be considered alongside the pathway

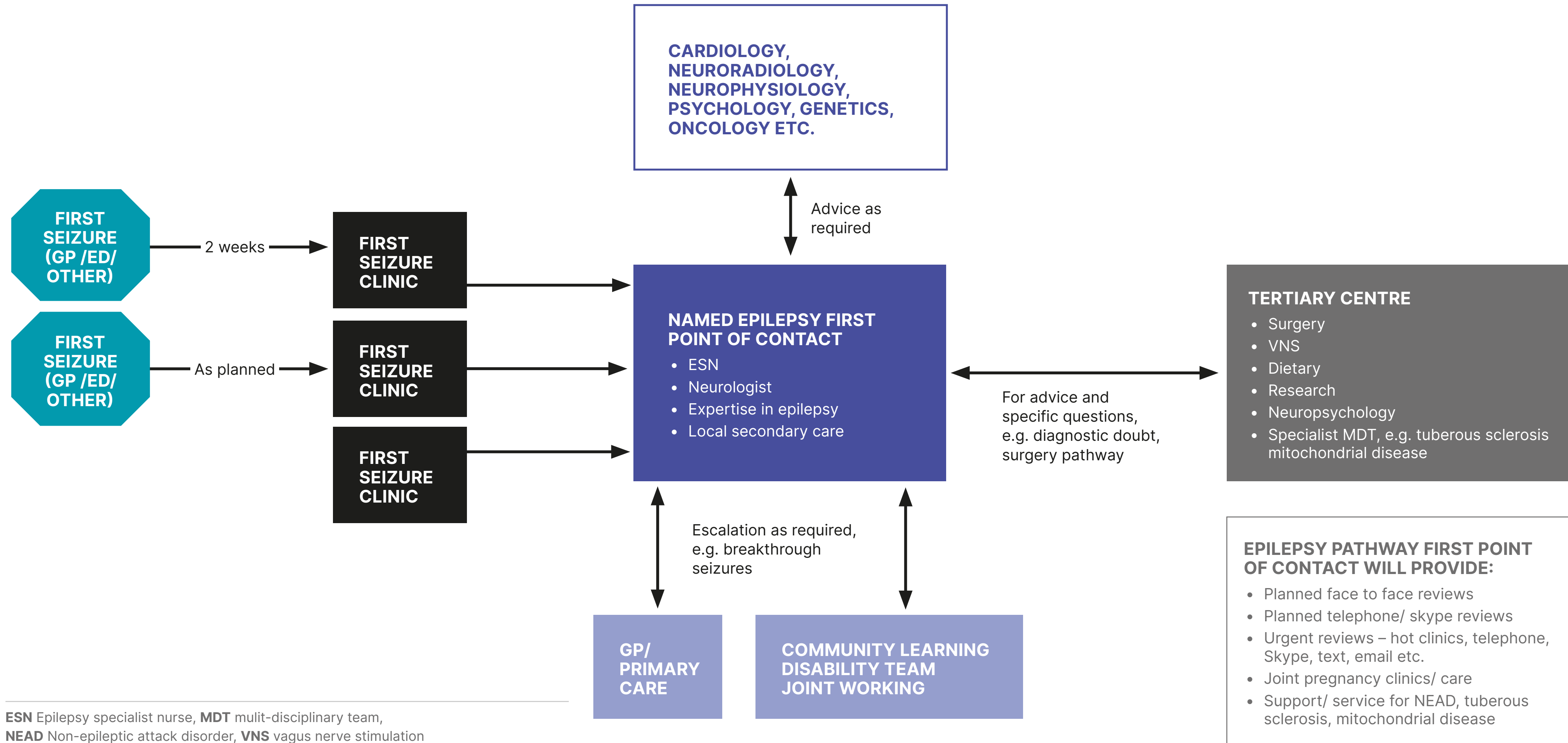
This epilepsy resource navigator tool is designed for commissioners, providers and professionals working with the epilepsy population in England. The tool identifies and directs you to the best available resources to commission, design and improve services for people with epilepsy, their families and carers. The information and resources in the tool can help local systems to deliver the NHS priorities for 2023/24 and the commitments in the NHS Long Term Plan, including addressing A&E waiting times and improving performance against the core diagnostic standard.

Neurological Alliance (2023)
Epilepsy resource navigation tool
for commissioners and providers

[VISIT WEBSITE](#)



Appendix: Referral pathways for the first point of contact



ESN Epilepsy specialist nurse, MDT mulit-disciplinary team, NEAD Non-epileptic attack disorder, VNS vagus nerve stimulation

Appendix: Clinical working group membership

Name	Profession	Organisation
Tony Marson	■ Workstream clinical lead, Consultant Neurologist	■ Liverpool University, The Walton Centre NHS Foundation Trust
Rohit Shankar	■ Consultant Developmental Neuropsychiatrist	■ University of Plymouth Peninsula School of Medicine
Melissa Maguire	■ Consultant Neurologist	■ Leeds Teaching Hospitals NHS Trust
Rhys Thomas	■ Consultant Neurologist	■ Newcastle University, Royal Victoria Infirmary Hospital
Dougall McCorry	■ Consultant Neurologist	■ University Hospitals Birmingham NHS Foundation Trust
Hannah Cock	■ Consultant Neurologist	■ St George's University Hospital NHS Foundation Trust
Mark Manford	■ Consultant Neurologist	■ Cambridge University Hospitals NHS Foundation Trust
Khalid Hamandi	■ Consultant Neurologist	■ Cardiff and Vale University Health Board
Phil Tittensor	■ Consultant Nurse for the Epilepsies	■ ESNA, Royal Wolverhampton NHS Trust
Sammy Ashby	■ Chief Executive	■ SUDEP Action
Julie Riley	■ Deputy Director of Strategy	■ The Walton Centre NHS Foundation Trust
Angie Pullen	■ Epilepsy Services Manager	■ Epilepsy Action (now Programme Lead at Epilepsy Research UK)
Jon Dickson	■ GP, Senior Clinical Lecturer	■ Sheffield University

Acknowledgements

- The SUDEP Action policy group for their input into the pathway.
- The organisations and individuals who supported the development of the pathway through the stakeholder consultation and workshops.

Appendix: Glossary of terms

C

Cannabidiol (CBD)

Cannabis derivative thought to have anti-epileptic effect in Dravet Syndrome and Lennox-Gastaut Syndrome. NICE Guidance expected October 2019.

Complex surgical resections

Surgical procedures to remove areas of the brain identified as causing seizures.

E

Electroencephalogram (EEG)

A recording of electrical brain activity in which small electrodes are attached to the scalp. An EEG is usually performed by the team in a neurophysiology department in a hospital.

Everolimus

Medicinal treatment for tumours and for focal onset seizures caused by tuberous sclerosis complex (TSC).

I

Invasive video EEG telemetry

A recording of seizures using video and EEG including electrodes placed into the brain or a grid of electrodes over the surface of the brain.

K

Ketogenic diet

A diet high in fats and low in carbohydrates, which can reduce seizures although it is not currently recommended by NICE.

N

Neurogenetics

Study of the genetic causes of neurological diseases.

Non Epileptic Attack Disorder (NEAD)

A disorder in which patients experience seizures, which have a psychological cause, as opposed to epileptic seizure that are due to abnormal electrical activity.

P

Positron emission tomography (PET) scan

Scans that produce images of the brain by detecting radiation given off by a radiotracer injected into a vein in an arm.

S

Single-photon emission computed tomography (SPECT)

A scan that measures blood flow in the brain, using a radioactive substance injected into the arm followed by a computed tomography (CT) scan. Measuring blood flow can help detect the origin of a seizure.

V

Video EEG Telemetry (vEEG)

A vEEG involves having an EEG whilst being videoed at the same time. Patients are often admitted to hospital for 5-7 days for this investigation.

Vagal nerve stimulation (VNS)

An implanted device that sends small electrical pulses to the vagus nerve in the neck. Impulses travel up to the brain to reduce seizures.

Appendix: References

22

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National Neurosciences Advisory Group c/o The Neurological Alliance (England)
www.nnag.org.uk

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

www.neural.org.uk

Email: info@neural.org.uk

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